

Consumer Focus Group Findings

Ten focus groups with people living with HIV/AIDS in King County were facilitated jointly by Public Health – Seattle & King County and AIDS Housing of Washington. A total of 66 individuals participated. A summary of housing-related comments from each focus group can be found in **Appendix II**.

- Across all focus groups, a significant number of participants indicated they had a history of homelessness or were at risk of homelessness.
- For many participants, housing instability and homelessness were factors in their lives prior to their diagnosis with HIV or AIDS.
- With only a few exceptions, nearly all of the focus group participants were relying on or in need of some form of housing assistance.
- Previous rental, credit, and criminal histories continue to serve as barriers to accessing housing for many participants.
- Current or former substance use continues to be a factor in many focus group participants' lives. A significant number of participants identified strong concerns about living in neighborhoods or buildings with open drug activity.
- Focus group participants said that waiting on lists for permanent housing from public housing authorities and other providers can take many months or years. In the interim, they rely on family, friends, shelters, and transitional programs for housing.
- Focus group participants had varying levels of understanding about the AIDS housing system and other community housing resources. A number of participants relied solely on their case managers to find housing while many others were able to secure housing through their own persistence and self-advocacy.
- Participants in many of the focus groups believe that eligibility for AIDS-dedicated housing should be open to everyone with HIV and AIDS. The existing inventory of housing units is prioritized for individuals with a qualified AIDS disability.
- In every group, participants said their primary concern was getting into and maintaining stable, affordable housing. With that goal in mind, the majority said they would like to live independently in a convenient and safe neighborhood.

Overview of Focus Groups

Focus groups were vital to obtaining qualitative, in-depth input from King County residents living with HIV/AIDS during the needs assessment process. Meeting in small groups gave participants the opportunity to discuss a range of issues related to their housing environments, needs, and preferences in more detail than participating in public meetings or completing surveys would typically allow.

Ten two-hour groups were conducted with people living with HIV/AIDS in King County. Public Health – Seattle & King County (Public Health) coordinated the groups for the Ryan White CARE Act needs assessment, which occurs every two years. The groups were organized by populations with similar demographics or characteristics to ensure broad representation and diverse consumer

input as required by the Ryan White CARE Act. Public Health recruited participants who had received medical care for the first time in King County within the past five years.

Sixty-six individuals participated in the process, which included 48 men, 17 women, and 1 transgender (male to female). In addition, 33 were African American/Black, 18 were White/Caucasian, 8 were Latino/Hispanic, 5 were Native American, and 1 was Asian/Pacific Islander. The race/ethnicity of one individual was unknown.

During the first hour of each focus group, Public Health staff asked questions related to access to medical care. During the second hour of each, AIDS Housing of Washington (AHW) staff asked questions related to housing needs and experiences. While the facilitators asked similar questions in each group, participants shaped the conversation by highlighting those issues of greatest concern to them. Participants were paid a stipend of \$30 for the entire session.

Table 24 summarizes the population, date, and number of participants for each of the consumer focus groups. Two additional focus groups were scheduled but cancelled due to low or no registration. One was for Asian/Pacific Islanders and the other for men of color who have sex with men and use injection drugs. Perspectives from individuals in those sub-populations were represented in other groups.

Table 24:
Consumer Focus Groups

Population	Date	Number of Participants
Injection Drug Users	October 24, 2003	6
White/Caucasian Men who have Sex with Men (MSM)	October 28, 2003	9
Latinos/Latinas	October 29, 2003	6
Formerly Incarcerated Persons	October 30, 2003	5
Current or Formerly Homeless Persons	November 6, 2003	11
Women	November 7, 2003 and December 12, 2003	6
Native Americans	November 13, 2003	5
African Americans/Blacks	November 14, 2003	7
Young Adults (under age 25)	December 9, 2003	4
MSM of Color	December 11, 2003	7

Issues Identified by Focus Group Participants

In each focus group, participants were asked to describe their current housing situation, including whom they lived with, the housing qualities they liked and disliked, and issues they had encountered while searching for housing. Participants were also asked to consider how their housing and support service options might be improved. Comments from each group are summarized in *Appendix II*.

Participants had a wide variety of experiences and needs, as well as opinions about the kind of housing and services that would be helpful for them personally and for people living with HIV/AIDS in general. Some common themes emerged from the focus group discussions, which are outlined below. Each theme is presented as a statement (in bold) and is followed by supporting comments.

Across all focus groups, a significant number of participants indicated they had a history of homelessness or were at risk of homelessness.

In every focus group, at least one participant—often more—had a history of homelessness and many were at risk of homelessness. Individuals cited many circumstances that led to their unstable housing, from the end of relationships and the desire to keep one’s HIV status confidential from family members to histories of substance use, mental illness, incarceration, limited employment, and simply lack of money.

A number of focus group participants were without housing at the time of the group. They were sleeping in shelters or motels, staying with friends, or living on the streets. Some said they had stayed in shelters previously and refused to return while others said they preferred to sleep outdoors. There were varying comments on cleanliness, personal safety, and privacy in Seattle-area homeless shelters. Some individuals who were living in shelters expressed concern about disclosing their HIV status and taking medications for fear of being asked to leave or not being able to keep confidential their HIV status. One participant stayed in shelters in other parts of King County, which are newer and perceived to be safer, and took the bus to Seattle for medical care. This participant also said he/she turned down offers from housing from family members because they did not know about his/her HIV status.

~
**“Jail was the only time
when my life was stable
enough to take medication.”**

*Focus Group Participant,
People with a history of
incarceration*

Participants had mixed experiences taking medications while living on the streets or in temporary quarters. One participant said that maintaining a medication regimen provided focus and structure to his/her day. Other participants actively chose not to start medications because they knew they could not adhere to the requirements. Still others said they attended the Day Health Program at Bailey-Boushay House and appreciated having a regular place to help them maintain stable healthcare.

~
Nearly all of the participants who had been homeless or were currently homeless shared frustrations with trying to get back on their feet financially and into stable housing. Money for move-in costs was cited as a barrier, as well as gaps in rental history. Participants stated that collecting and saving enough money to pay for move-in costs, such as application fees, utility deposits, and security deposits was difficult. Some suggested more community resources to help with up-front housing costs. Those who persistently advocated for themselves appeared to be most likely to get into desired housing programs.

For many participants, housing instability and homelessness were factors in their lives prior to their diagnosis with HIV or AIDS.

Many focus group participants said they have had little or no housing stability for much of their adult lives. A few individuals reported learning they were HIV-positive while living in a shelter. Others said they were homeless prior to moving to Seattle-King County, and many spoke of moving around between family, friends, housing programs, and other cities and states. One participant said he/she had run away from foster care placements at a young age and lived on the streets, in a car, and in other kinds of temporary housing.

For many, housing instability and frequent moves were not a result of HIV/AIDS, but endemic to lives disrupted by poverty, substance use, mental illness, or limited life skills. Some focus group participants said they moved to King County for better services, to live in a more supportive community, and to keep confidential their HIV status from family or friends.

~

“Nothing felt so good as the first time I walked into my new apartment and locked the door behind me. I didn’t know what a relief that would be.”

*Focus Group Participant,
People who currently are or formerly
have been homeless*

~

It was clear from most focus group participants that HIV/AIDS is not the only, and often not the most pressing, issue in their lives. Many people said they were able to qualify for existing housing programs for reasons other than HIV/AIDS.

With only a few exceptions, nearly all of the focus group participants were relying on or in need of some form of housing assistance.

In each of the focus groups, individuals stated they were currently seeking a stable place to live or hoping to move into something better, more permanent. Other participants said they had received transitional or permanent housing support from programs such as Multifaith Works/MAPS, Lifelong AIDS Alliance, the Lyon Building, Shelter Plus Care, and Section 8. With no assistance,

~

“If I can’t find permanent housing in the next 16 months, I’ll be back out on the streets again.”

*Focus Group Participant,
People with a history of incarceration*

~

individuals were most likely to be homeless or at imminent risk of homelessness. Some of the individuals participating in transitional housing or residential treatment programs expressed their anxiety about where they would find and qualify for permanent housing.

The group most likely (although not exclusively) to be in stable, long-term housing was comprised of White/Caucasian men who have sex with men (MSM). A few of the participants were homeowners or living with a partner or family member who helped pay for housing.

Participants in this focus group also appeared to have high levels of knowledge about the AIDS housing system and related community resources, as well as the self-advocacy skills to access those resources. Still, one individual who owned a home reported feeling the competing demands between maintaining a mortgage and covering healthcare costs. He said he worked more than one job to afford his home and private insurance because he was not eligible for any other form of assistance.

Some participants expressed frustration at not being able to work without risking benefits such as Supplemental Security Income (SSI) or Social Security Disability Income (SSDI). One young adult addressed the challenge of competing with older, more skilled workers for entry-level jobs. The lack of benefits from low-wage jobs concerned many of the participants who were working or looking for work, as well as the ability to maintain employment during extended illnesses.

~
“It’s not age. It’s money. I could be 50, but I’m still broke.”

Focus Group Participant, Youth and young adults (under age 25)

~

Previous rental, credit, and criminal histories continue to serve as barriers to accessing housing for many participants.

In addition to financial barriers, participants identified other challenges to securing housing with public agencies, housing programs, and private landlords. Poor rental and credit histories were often cited as lingering barriers that can follow a tenant for many years. Conversely, an individual may qualify for housing but a partner or spouse’s history may be cause for denying a rental application. One participant expected to be evicted only days following the focus group. He/she had been able to take advantage of a private rental move-in special but could not maintain the monthly rent. As a result, this individual’s rental history and credit score will be damaged and finding a new place in the future will likely be difficult. Some of the participants who were involved with transitional housing programs said they very much appreciated the chance to improve and restore their rental and credit histories.

~
“Money is not the issue. I cannot get housing because of my felony record.”

Focus Group Participant, MSM of color

~

Participants in the focus group for people with a history of incarceration expressed the most frustration about barriers to housing which placed them at a significant risk of homelessness. Most of the participants who had been released from jail or prison recently had returned to Seattle with no preparation for the transition or plan for housing. One participant was able to find transitional housing while still in prison through his/her own self-

advocacy and connections made with agencies prior to his/her release. Public housing authorities and many community housing programs in King County are willing to work with people with criminal histories; however, individuals with specific drug felonies and those released within the past two to five years have the most difficult time finding housing that is subsidized, as well as housing on the private market.

Current or former substance use continues to be a factor in many focus group participants’ lives. A significant number of participants identified strong concerns about living in neighborhoods or buildings with open drug activity.

Substance use was an issue identified in almost every focus group. A few participants identified that they were currently using drugs or alcohol and many said they were continuing to struggle with sobriety. The strongest concern raised in most of the focus groups was the importance of living in a neighborhood or building away from high drug activity.

Many participants shared their experiences of living in shelters, emergency housing, and other environments where substance use was common and visible, and the personal challenges those situations created as participants struggled to stay clean and sober. The most common recommendation for housing improvement was to create more emergency, transitional, and

permanent housing opportunities that are away from active drug trafficking areas and to improve supports for people struggling with addiction.

One participant said he/she moved directly from a residential substance use treatment program to a building in downtown Seattle where substance use is allowed and did not maintain sobriety for very long. Some of the participants who had recently been released from prison or jail said they had heard that parole officers refused to release some inmates to addresses in areas known for high drug activity. Another individual said he/she would like to attend a support group for people with HIV/AIDS in a particular neighborhood, but does not feel personally strong enough to resist the temptation of drugs or alcohol to even get on the bus to go to that area.

In some of the groups, participants discussed their perceptions of the purpose of the Lyon Building and resident activities that may not have been based on first-hand or current knowledge and experience. The Lyon Building was designed for homeless, low-income, single adults with multiple disabilities related to HIV/AIDS, mental illness, and chemical dependency. One participant said he/she had been told many years ago that the Lyon Building provided clean and sober housing. Other participants said they had voluntarily turned down or been dissuaded from living in the Lyon Building because of their access to drugs and alcohol in that environment.

Focus group participants said that waiting on lists for permanent housing from public housing authorities and other providers can take many months or years. In the interim, they rely on family, friends, shelters, and transitional programs for housing.

Many focus group participants reported waiting many months, even years, for permanent housing in King County. Experiences varied based on agency, year, and persistence. Some participants thought they were on one or more waiting lists but could not say for certain. They relied on case managers and housing staff for information and action. Those who have been able to get on the waiting list for Section 8 expressed frustration at the length of time it took, or is taking, to get a voucher and the lack of information they have received about the status of their application. Others noted that they have not even been able to get their names on Section 8 waiting lists that are closed.

~

“I realized a dollar goes a longer way outside of Seattle.”

*Focus Group Participant,
People who currently are or
formerly have been homeless*

One participant said he/she was able to get a Section 8 voucher for housing outside of Seattle and felt that opened up more housing options. Another participant said he/she had been turned down for an apartment only a few days prior to the focus group and did not understand why the landlord did not approve his/her application. The participant planned to continue working with a housing advocate to find a place to live. Some participants said they did not know where to go for help or what programs they might qualify for.

Some individuals said they had received housing from Lifelong AIDS Alliance without waiting and some others said they had to wait in the past. Overall participants wanted all agency waiting lists to move faster and to be kept informed of their status.

Focus group participants had varying levels of understanding about the AIDS housing system and other community housing resources. A number of participants relied solely on their case managers to find housing while many others were able to secure housing through their own persistence and self-advocacy.

Knowledge and self-advocacy varied across the groups. Many participants were connected to or knew about resources available from Lifelong AIDS Alliance. Others worked only with their primary case manager where they received medical or mental health services. Some individuals did not know exactly how they were able to access their current or previous housing because their case managers handled all of the arrangements. Still, a few other participants were able to navigate the service and housing systems on their own to garner the resources they needed.

Participants identified information dissemination and staff turnover as two key areas for improvement. For people who were relatively new to King County and not connected to local services or organizations, access to information remained a priority for learning about the community and where to go for help. For example, one participant who had recently moved to Seattle and was living in a shelter suggested billboards and bus signs as easily accessible places to get information about HIV/AIDS services.

In addition, many focus group participants relied on the knowledge of agency staff to help them navigate the service and housing systems. Participants spoke about high staff turnover and feeling uncomfortable with the ongoing process of sharing personal information with new workers. Many said it was difficult to start over with a new case manager and sometimes challenging while the case manager became fully aware of community resources, systems, and policies. In particular, participants in the young adult group felt especially connected to the relationships they had developed with staff and expressed the importance of having consistent contact with that individual.

Participants in many of the focus groups believe that eligibility for AIDS-dedicated housing should include everyone with HIV and AIDS. The existing inventory of housing units is prioritized for individuals with a qualified AIDS disability.

In many of the focus groups, participants expressed concern and frustration about their inability to access housing, particularly in the current AIDS housing system. Many said they have heard about housing resources for people with AIDS, but do not qualify because they do not have a qualified AIDS disability (an eligibility criteria at the time this plan was written). Some of the participants in the young adult focus group expressed resentment because they believed they were not eligible for any housing assistance as single adults, with no disability, and no dependents. They were concerned about their long-term prospects for health and well-being if they could not maintain employment and find some kind of housing stability.

~
**“If you don’t get housing, how
can you get grounded? I thought
the system was here to help
people like me.”**

*Focus Group Participant,
Injection drug users*

~

In every group, participants said their primary concern was getting into and maintaining stable, affordable housing. With that goal in mind, the majority said they would like to live independently in a convenient and safe neighborhood.

For participants who were not in stable, financially viable housing, they simply wanted to find a place they could call home. Without some kind of financial assistance, however, this was not an option for most. These individuals were seeking information and support to determine what opportunities, if any, might be available to them. Some believed they had no options left. Others said they struggled with paying rent and affording other necessities such as utilities, food, and childcare. For individuals who were receiving housing assistance, they appreciated living in a place they could afford and stay in for a longer period of time. Notably, participants who were in permanent housing spoke about their relief, and even happiness, at being in a stable situation.

When asked what housing characteristics participants preferred or appreciated, the majority said they would like to live independently or alone, with a supportive community of family, friends, or peers nearby. In addition, participants wanted to live in a safe environment in a clean neighborhood. Being close to transportation, parking, stores, and medical care were identified as priorities by many participants; however, in general people were able to get to medical appointments and other services even when they lived outside of Seattle.

Participants were also asked what improvements they would make to the housing system in King County to better support individuals and families. Some of the suggestions included:

- Ongoing rental assistance that extends beyond one month or a limited dollar amount
- More transitional living environments
- More opportunities to live independently
- Better information about housing options
- Eliminate credit checks for people on disability
- Safeguard against discrimination
- Options for living with partners in transitional and permanent housing programs
- Stronger support system
- In-reach at prisons and jails
- Assistance while in the hospital or unable to work due to illness
- More outreach in shelters
- Better pay for case managers